

***Next Meeting – Monday, September 10, 2007 – 2 PM
Dover Air Force Base
Dover, Delaware***

**STATE COUNCIL FOR PERSONS WITH DISABILITIES
BRAIN INJURY COMMITTEE
August 6, 2007 – 2:00 PM
APPOQUINIMINK STATE SERVICE CENTER
MIDDLETOWN, DELAWARE**

PRESENT: John Goodier, Chair; Brian Hartman, Co-Chair; Ray Brouillette, Easter Seals; Jim Burcham, BIAD; Dr. Jane Crowley, A.I. DuPont Hospital; Tony Horstman, SCPD; Lora Lewis, DPH; Mike Merrill, VR/U.S. DVA; Tom Parvis, DVR; Al Rose, DDC; Kyle Hodges, Staff and Linda Bates, Support Staff

ABSENT: Virginia Corrigan, Christiana Care; Laura Cygan, DPH; Aaron Deede, Consumer; Ellen deVrind, Christiana Counseling; Linda Heller, DSAAPD; Dr. Dan Keating, Bancroft Neurohealth; Janet Leitch, Consumer; Chris Long, DDDS; Beth Mineo Mollica, DATI; Dr. Bradley Meier, DPC; Ann Phillips, Parent; Liz Schantz, Consumer; Dawn Stewart, Healthy Living and Wendy Strauss, GACEC

GUESTS:

Mary Sue Jones, Division of Public Health (DPH)
Doug Rich, Division of Public Health (DPH)
Lisa Bond, DHSS/DSAAPD
Zel Cannon, DHSS/DSAAPD

CALL TO ORDER

The meeting was called to order at 2:10 PM.

APPROVAL OF MINUTES

Motion was made, seconded and approved to accept the May 7, 2007 meeting minutes as submitted.

AGENDA ADDITIONS/DELETIONS

- None.

BUSINESS

Trauma Registry & Hospital Discharge Data—Mary Sue Jones and Doug Rich

Mary Sue Jones provided materials on the Delaware Trauma System Registry. One Registry for TBI patients was a FYI hand-out that is specific to TBI statistics from 2001 to 2005 from Trauma Centers in Delaware. In addition, a copy of the Trauma Registry that the hospital must complete was provided to all.

Mary Sue provided an overview of some of the highlights of the hand-out entitled Delaware Trauma System Registry which consisted of the History, Functions, Components and Management. A summary of this information is below.

It is an inclusive system which includes: all patients; all providers and facilities, and all injury data. The goal is to match every trauma care facility's resources with the needs of injured patients.

Trauma System Goals

- Get each Patient to the Right Facility in the Right amount of Time
- Decrease Morbidity & Mortality from Injury
- Save Health Care Dollars
- Preserve Lives & Livelihoods

Trauma Facilities

In Delaware, there are eight acute care facilities that have ER departments. In addition, Delaware has the following "trauma centers".

- Regional Trauma Center Level 1 – Christiana Hospital
- Regional Trauma Center Level 2 – none
- Community Trauma Center Level 3—
Bayhealth Medical, Kent General
Beebe Medical Center
DuPont Hospital for Children
Peninsula Regional Medical Center, MD – reciprocity
- Participating Hospital – Level 4
Bayhealth Medical, Milford Memorial
Nanticoke Memorial Hospital
St. Francis Hospital
Wilmington Hospital

What is a Trauma Registry?

- Computerized data base required of all Trauma System hospitals. DE software – "Collector"
- Specified hospital patient population
- Data points:
Collected from medical record
Used to generate reports, information

This was an unfunded mandate until 1996—one year of funding for Mary Sue; legislation was passed for Mary Sue’s salary from Public Health’s funds.

This database is on PCs in each of the hospitals; data is entered by the hospital into the database; participation is voluntary and not mandatory. Once participating, standards have to be met on data that is sent to Mary Sue.

Crash Outcome Data Evaluation System (CODES) is funded by CDC. Laurie Lynn handles the motorcycle accidents and Mary Sue will e-mail Kyle this information. The Trauma Registry does not link into the CODES project. The linkage project records hospital discharge data, police crash and ambulance data—all three together. There is no DE out-patient emergency department discharge data. The Trauma Registry ends at discharge from acute care. Mary Sue gets admissions quarterly from the hospitals. There is no trauma registry supervisor at DPH. The reports really capture more moderate to severe injuries.

In reference to a TBI registry, it was suggested to use the CDC definition of TBI. Doug Rich from the Division of Public Health will send a list of the communicable diseases that must be reported. The Cancer Registry may be a better option. There is legislation regarding this and it is mandatory for physicians to report information to the cancer registries. Kyle will check who is the contact for the cancer registry. Legislation would have to be established for funding incentives for trauma centers. Maryland has an extra \$1 for license plates for physicians to get refunded. Some states get 5 cents on many violations. Mary Sue will send a copy of the report on recommendations for funding incentives to Kyle.

Doug Rich from DPH gave out an overview on the hand-out on “Hospital Discharge Data and Traumatic Brain Injury”. Below is a summary.

States with Advanced TBI Registry Systems

- There are 10 or less states with TBI registries. Florida and Minnesota are two of the advanced states.
- Most of these states supplement Trauma registry data with Hospital Discharge Data (HDD) and Medicaid linkages, along with a medical chart review.
- Need to have legislation passed for TBI registry information.

It was decided that a group will meet to address this issue —Betsy, Jane, Doug, Mary Sue and Kyle.

Hospital Discharge Data—Delaware

- Uniform Health Data Act...1995 DE Code (on a quarterly basis the hospital submits all in-patient discharges)

- Approximately 100,000 inpatient discharges per year.
- Diagnostic Codes (ICD-9) are specific to TBI
- Injury Codes (E codes) TBI
- Data comes by hospital billing systems
- Takes one to two years to process annual data—2004 is our most recent
- Privacy standards (cannot release personal identifiers).
- Annual report is done.

TBI injury rate per 100,000

- 1999 = (62.6) per 100,000 persons Delaware resident rate.
- 2002 = (62.9) Delaware resident rate.
- The above are one year rates.
- 2002-2004 = three year rate for TBI hospitalizations is 66.2
- TBI morbidity going up.

ABI Waiver

Lisa Bond and Zel Cannon from DSAAPD gave the following update.

- The draft application has been sent to CMS; comments are due back by August 10
- The final application will be formally submitted to CMS
- The waiver implementation date is still December 1, 2007.
- DSAAPD is recruiting providers.
- DSAAPD has received 29 letters of intent from multiple providers
- Services in the waiver include, but are not limited to, adult day care; assisted living; day habilitation; personal care, respite services; emergency services and cognitive services
- Medicaid intends to publish the regulations on 10/1
- The eligibility will now include individuals who acquire a brain prior to their 18th birthday although they would still need to be age 18 or older when they receive DSAAPD waiver services.

Lisa will send to Kyle the DDDS/DSAPPD MOU that has been signed.

- For FY 08, the waiver will be for seven months with a cost of \$1.4 million total – includes \$700,000 federal dollars plus \$700,000 in state match.
- Need to request the next 5 months funding for FY 09.
- Year One—50 people served; Year two—60 people served; Year three—70 people served
- The waiver is good for three years
- Lisa will send rates for services.
- Still need to determine how slots are to be filled. Some people will switch from E&D and AL Waivers and need to look at the current waiting list.

At Brian's request, Lisa will check/research child waiver information.

PATI Report

I. DOE Final LD Eligibility Regulations [11 DE Reg. 184 (August 1, 2007)]

Brian analyzed the proposed version of Department of Education special education eligibility regulations in June, 2007. The SCPD and GACEC then submitted conforming comments to the Department. The most important aspect of the standards for students with TBI was the elimination of the traditional practice of involving a school psychologist in assessment of learning disabilities. The 2006 IDEA regulations authorize LD assessment to be conducted without a school psychologist. See attached 34 C.F.R. §300.308(b). Since children who are struggling academically are most often assessed under LD criteria, the Councils recommended that the State exceed Federal standards by requiring the involvement of a school psychologist in this context. The Department rejected the recommendation.

Historically, many children with TBI have been initially assessed and/or classified under the LD category. School psychologists receive specialized training in assessment which facilitates identification of students with TBI. Allowing an evaluation team to be composed solely of teachers undermines the validity and reliability of assessment. As a result, students may not be identified as IDEA-eligible or may be misclassified based on a lack of sophistication. For example, although the regulations [attached 34 C.F.R. §300.309] provide that a child can qualify as LD solely based on math calculation or math problem solving deficits, the regulations allow a reading teacher or speech pathologist to conduct the assessment.

Parents of students with suspected TBI should be encouraged to affirmatively request the involvement of a school psychologist in any IDEA eligibility assessment. Districts have discretion in this context.

II. DOE Final ESY Regulations [11 DE Reg. 181 (August 1, 2007)]

Brian has prepared the following italicized analysis of DOE summer school regulations to present to the SCPD Policy & Law Committee on August 9.

The SCPD and GACEC commented on the proposed version of these regulations in June, 2007. The DOE acknowledged receipt of GACEC comments but not SCPD comments. The DOE effected no amendments based on the Council's observations. The principal problem with the regulation was repeal of a regulatory note described below.

The Council strongly objected to deletion of a note clarifying that students with classifications of SMH, TMH, autism, deaf-blindness, TBI, and some physical disabilities are automatically entitled to ESY under statute [Title 14 Del.C. §1703(e)(f)]. The statute is based on the premise that such conditions are commonly recognized as severe disabilities. The DOE declined to restore the note, commenting as follows:

The Department believes the normal school year is sufficiently defined in Title 14 of the Delaware Code, and the statute adequately addresses the specific populations being served. Given the detailed provisions in Title 14, no change to the regulation is necessary.

This response is inane. The DOE regulation is contrary to the statute. It affirmatively disallows categorical statutory eligibility by exclusively limiting ESY to: 1) individual IEP team determination [§6.2]; and 2) qualification under 1 of 5 individual standards [§§6.1 and 6.5]. There is no exception for students who automatically qualify for ESY under statute. Furthermore, the rationale that the “normal school year is sufficiently defined in Title 14” is inaccurate. By statute [Title 14 Del.C. §1049], local educational agencies can establish their own school years as long as they amass a certain number of hours. For example, one district could legally adopt a 7 hour school day with 152 school days over 8 months while another district could adopt a 6 hour school day with 177 school days over 9 months. Finally, the DOE regulation does not refer to the normal school year as defined in Title 14. To the contrary, it refers to “the normal school year of the public agency” (a/k/a district or charter school). Thus, DOE’s regulatory reference to “normal” or “regular” school year does not even implicitly refer the reader to Title 14 Del.C. §1703(e)(f).

Brian recommends that the SCPD consider preparation of a letter to the Governor (and her counsel) and/or House and Senate Education Committee members. Attached are the Committee membership lists. Brian has also recommended that the SCPD solicit endorsements of the letter so that it can be submitted with a list of supporting agencies (e.g. ARC; BIA; DDC; GACEC; Easter Seal; Autism Society; PIC; DLP; CODE).

Brian also recommended that agencies represented on the SCPD Brain Injury Committee authorize the SCPD to include their endorsement of the proposed letter. The rationale is very simple. The attached State statute confers a right to automatic ESY to students with TBI. The attached regulation contradicts the statute and subjects all students with TBI to an individual assessment of eligibility for ESY services. BIA, DDC, Easter Seals, and DVR agreed to support the SCPD letter consistent with the aforementioned analysis and strategy.

It was added that Kyle will solicit endorsements of the letter from other agencies. In addition, Kyle will contact George Meldrum for support and Abe will ask DCMH for support. Tony will check with the DDDS Advisory Council.

III. DDDS Eligibility Regulation

On July 1, 2007 the Division of Developmental Disabilities Services published a proposed eligibility regulation which deletes the existing authorization to cover individuals with brain injury. The DLP and other agencies are spearheading the effort to restore “brain injury” and “other neurological disorders” to the eligibility standards. The Division plans to consider the comments received in July and reissue a revised proposed

draft in September. This is very important initiative since it may effectively bar individuals with TBI from access to DDDS services.

Brian and Tony attended the hearings.

IV. S.B. No. 17 (Low-Speed Vehicles)

This bill authorizes 4-wheeled “low speed vehicles” which can attain speeds between 20-25 mph to travel on Delaware highways with a speed limit of not more than 35 mph. They are exempt from safety inspections based on the rationale that the 35 mph highway speed restriction would prevent the vehicle from reaching the DMV lanes. Only licensed drivers may operate the vehicles and insurance is required. The vehicles are described as “not golf carts” but electric vehicles for local commuting. This bill was not on the Committee’s “radar screen” and was signed by the Governor on April 14, 2007. It would have been preferable to address safety issues more comprehensively.

Given enactment, Brian recommends no action.

V. Brain Injury Tool Kit

The Centers for Disease Control and Prevention (CDC) has issued a TBI tool kit for physicians. It includes the attached fact sheets on preventing concussions and “a palm card for the on-field management of sports-related concussion”. These materials may be of use in the Committee’s sports-related concussion training initiative.

Abe will forward information to Kyle. Jane will present at a conference sponsored by Kevin Charles of the Director of the Interscholastic Athletic Association.

VI. NDRN National PATBI Overview

The P&A trade organization, the National Disability Rights Network, published a national overview of the PATBI program in its June, 2007 newsletter. It highlights a Delaware case. It also provides perspective on the variety of contexts in which services are provided. Healthcare and education are the most prevalent contexts of advocacy nationwide.

VII. CDS Preventing Secondary Conditions Project

The Center for Disabilities Studies has received a multi-year grant to prevent “secondary conditions” among persons with disabilities. For example, persons with TBI may be at risk for development of depression. See article under Par. VIII below. The project also targets “refining Delaware’s ability to monitor health and wellness issues for people with disabilities”. This may overlap with the Committee’s desire to establish a TBI registry or

otherwise include TBI-related data collection. Brian have joined the project's advisory council.

This project is a follow-up to Dr. Tom Kelly from Public Health's 2010 project.

VIII. Sports-related Concussion

The NFL recently convened a symposium on sports-related concussion. There was considerable disagreement among the participants concerning the long-term effects of TBI.

IX. Seat Belt Statistics

The Delaware Office of Highway Safety recently announced that seat belt usage has increased in Delaware from 67% in 2001 to 86% in 2007. It attributed the increase to enforcement of seat belt legislation, i.e., the "Click It Or Ticket" initiative.

X. Aggressive Motorcyclist Campaign

Consistent with a July 25, 2007 News Journal article, the State is targeting aggressive motorcyclists. In 2006, there were 11 deaths and 254 injuries attributable to motorcycle accidents. In July, 2007, there were already 9 deaths. Apart from more active police deterrence of unsafe driving, the State is promoting enrollment in safety courses.

XI. Bike Helmet Strategies

As a complement to the Committee's support of the bike helmet bill, there are several strategies to promote helmet use. For example, both New Jersey and Maine collaborated with merchants and police by obtaining small rewards (e.g. \$5 gift card) that police could distribute to kids wearing helmets. The Maine program was called "Save A Brain" campaign. Other initiatives include free distribution of bike helmets and training events. Consistent with the attached June 16, 2007 News Journal article, the Committee could consider contacting the sponsors of the "Use Your Head Bike Safety Fair" to assess prospects for a more expansive, collaborative initiative in Delaware.

Senator Margaret Rose Henry has assigned a number to the bike helmet bill (S.B. 174) which will be introduced in the next legislative session.

Disabilities Law Program—Protection & Advocacy for TBI (PATBI)— Draft FY '08 Priorities (July 31, 2007)

Brian presented the above draft plan to the BIC. This is a grant for \$50,000. Motion was made, seconded and approved to accept the July 31, 2007 draft Disabilities Law Program FY '08 Priorities as submitted.

ANNOUNCEMENTS

The September 10 2 pm meeting will be held at the Dover Air Force Base (DAFB) in Dover. Mike Merrill has arranged a one hour presentation on the “Transition Assistance Program”. After that, there will be a one hour BIC meeting. Kyle will make arrangements for a State van to transport members from the Blue Hen Conference Center in Dover at 1:30 pm to the DAFB. Kyle will send out an e-mail to all asking for an attendance response.

Jim Burcham has been asked to have a BIAD display at a “Bikes and Blues” festival to be held on August 18 in downtown Newark.

ADJOURNMENT

The meeting was adjourned at 4:30 pm.

Respectively submitted,

Kyle Hodges
SCPD Administrator